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## GENETIC SCREENING OF CHILDREN: THE U.K. POSITION

*Sheila A.M. McLean\**

The questions raised by genetic diagnosis and screening of children highlight some of the protectionism, contradictions, and tensions that often characterize our attitudes toward children. Virtually every society offers special protections to children. The status of childhood, with all of its assumed or real vulnerability, is offered respect. Children are seen as lacking autonomy, and therefore, incapable of reaching their own decisions. This view has led to the principle that children are to be protected from the consequences of their behavior by laws that, for example, preclude them from entering into legally binding contracts or from being held criminally responsible for their actions.

On the other hand, society also seeks to offer children the widest possible range of rights and the maximum protection of their interests, by giving them powers whenever possible. As a corollary, children must also have the right to be protected from the inappropriate or invasive decisions of others. Although these dual goals of protection and empowerment may seem entirely complementary, there is no doubt that they may sometimes come into conflict. Therefore, a balance is required. Striking such a balance, however, is not always easy, especially when it is impossible to make simplistic assumptions about what really is in the best interest of the child.

Of particular interest, is the question of a child's health. Society seeks to maximize the provision of health and health care services to children consistent with both traditional and more modern pronouncements, such as the United Nations Convention on the Rights of the Child.<sup>1</sup> While this may seem like a straightforward translation into reality of the protectionist approach outlined above, there is the potential for conflict between

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1. *Convention on the Rights of the Child*, U.N. GAOR 3d Comm., 44th Sess., Agenda Item 108, U.N. Doc. A/Res/44/25 (1989); *see also* CHILDREN, RIGHTS AND THE LAW (Philip Alston et al. eds., 1992) (providing a comprehensive discussion of the U.N. Convention on the Rights of the Child).

the protectionist and empowerment approaches. In order to safeguard children's health, it is necessary to act both preventively and therapeutically. It is essential for both prevention and therapy to obtain knowledge about conditions that either are specific to children, or are best able to be cured if caught early. However, acquiring the requisite knowledge for successful prevention and therapy is not without its costs. Acquisition of that knowledge may require the use of children in both therapeutic and controversial nontherapeutic research. The paradox then may be that in order to protect *some* children, we need to use other children as subjects of research to gain the knowledge necessary for prevention and therapy.

Like adults, children are subject to disorders that are solely or substantially caused by genetic factors. In 1985, Daniel Kevles estimated, "[g]enetic and chromosomal illnesses or malformations are reported to account for between twenty and thirty percent of all pediatric hospital admissions."<sup>2</sup> More recently, in 1992, J.K. Mason and R.A. McCall Smith suggested that, "the proportion of childhood deaths attributable wholly or partly to genetic factors runs at about 50%."<sup>3</sup> According to the British Medical Association, "[g]enetic and part-genetic diseases affect one in every twenty people by the age of 25 and perhaps as many as two in three people during their lifetime."<sup>4</sup> In light of this evidence, it cannot be disputed that genetic disorders exact a cost on individuals and society as a whole. Following the negative uses of genetics research in countries as disparate with respect to treatment of human rights as the United States and Nazi Germany,<sup>5</sup> the science of genetics had for some time been viewed with considerable ambivalence if not outright hostility. Over the years, however, advanced understanding about the role of genes has rehabilitated the science of genetics.

The resurgence of genetics is exemplified most sharply by the interest generated by the Human Genome Project, on whose back much of the "new" genetics rests.<sup>6</sup> This global attempt to identify the blueprint of

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2. DANIEL J. KEVLES, *IN THE NAME OF EUGENICS: GENETICS AND THE USES OF HUMAN HEREDITY* 291 (1985).

3. J.K. MASON & MCCALL SMITH, *LAW AND MEDICAL ETHICS* 123 (4th ed. 1994).

4. BRITISH MEDICAL ASSOCIATION, *OUR GENETIC FUTURE: THE SCIENCE AND ETHICS OF GENETIC TECHNOLOGY* 1 (1992).

5. See Sheila McLean, *The Right to Reproduce*, in *HUMAN RIGHTS: FROM RHETORIC TO REALITY* 99, 111 (Tom Campbell et al. eds., 1986); see also Sheila A.M. McLean & Dieter Giesen, *Legal and Ethical Considerations of the Human Genome Project*, 1 *MEDICAL L. INT'L* 159 (1994) (highlighting important legal and ethical issues raised by the Human Genome Project).

6. See OFFICE OF ENERGY RESEARCH & OFFICE OF HEALTH AND ENVIRONMENTAL RESEARCH, U.S. DEPARTMENT OF ENERGY, *HUMAN GENOME 1991-92 PROGRAM REPORT*

every individual's genetic makeup has captured public attention in a way that is unusual for a scientific venture. Although people outside the scientific world, and many within it, fail to understand the sophisticated science of genetics, a plethora of writing addressing its legal, ethical, and social implications has grown.<sup>7</sup>

Although the "new" genetics has a more respectable face than might have been predicted given its recent history, this is not to say that it is regarded as a universal good. As Thomas Murray points out, "[s]cientific research into human genetics has been a continuing source of intriguing, and at times formidable, ethical issues."<sup>8</sup> Moreover, despite the pleas of some commentators that "the widespread fear of genetics cannot be justified" and that "the research community should speak out strongly to defend the good sense of what it is about," many people are as afraid of the implications of genetic information as they are astonished at its capacity, and hopeful about the good it may ultimately offer.<sup>9</sup>

One concern is the potential for discrimination based on genetic information, particularly if the information is inadequately protected. As the Danish Council of Ethics has said:

Just as persons found through screening to have a particular gene or chromosome composition may happen to feel abnormal or outright ill[,]. . . so may others react to the persons involved by giving them a wide berth. The detection of certain genetic traits can thus form the basis for branding certain persons and groups among the population, with the possibility of discrimination proper as a result.<sup>10</sup>

This discrimination may take place in education, health care provision, insurance, employment, and a host of other areas of life.

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iii (1992) (stating that the purpose of the Human Genome Project is to gain "complete knowledge of the organization, structure, and function of the human genome—the master blueprint of each of us").

7. See, e.g., WALTER BODMER & ROBIN MCKIE, *THE BOOK OF MAN: THE HUMAN GENOME PROJECT AND THE QUEST TO DISCOVER OUR GENETIC HERITAGE* (1994); 1 SCIENCE AND TECHNOLOGY COMMITTEE, HOUSE OF COMMONS, *HUMAN GENETICS: THE SCIENCE AND ITS CONSEQUENCES* (1995) [hereinafter COMMITTEE REPORT]; TOM WILKIE, *PERILOUS KNOWLEDGE: THE HUMAN GENOME PROJECT AND ITS IMPLICATIONS* (1993); Sheila A.M. McLean, *Mapping the Human Genome—Friend or Foe?* 39 SOC. SCI. & MED. 1221, 1221-27 (1994); McLean & Giesen, *supra* note 5, at 159-75.

8. Thomas H. Murray, *Ethical Issues in Human Genome Research*, 5 FASEB J. 55, 55 (1991).

9. John Maddox, *New Genetics Means No New Ethics*, 364 NATURE 97, 97 (1993).

10. THE DANISH COUNCIL OF ETHICS, *ETHICS AND MAPPING OF THE HUMAN GENOME* 60 (1993) [hereinafter DANISH COUNCIL OF ETHICS].

Of course, genetic information is not unique in this respect. The most obvious parallel comes from those who are thought to be, or actually are, HIV-positive. The stigmatization of and discrimination against these individuals is a clear reminder of the potential problems lurking beneath the diagnosis. When this potential for discrimination is coupled with the vulnerability of the child, it seems that any approach to the dilemmas of the use of genetics with respect to children must be particularly sensitive to the interests being served and the rights that are being respected. Yet, for reasons already outlined, children (and embryos and fetuses) may provide a particularly appropriate group to be targeted by advances in genetic knowledge, particularly with the availability of prenatal screening, neonatal diagnosis, and the possibility of screening for late-onset conditions.

There are, arguably, few who would adopt a wholly, or even substantially, negative approach to the "new" genetics. Notwithstanding the fears already mentioned, society is sufficiently aware of the extraordinary promise offered by genetic knowledge. In addition, it seems likely, as with HIV infection, that many residual concerns will dissipate when diagnostic capacity is equalled by therapeutic potential. For this reason, research into genetics is essential. Although "[u]nderstanding does not always presage more effective treatment, . . . the promise is high."<sup>11</sup>

The desired outcome of much of the activity in the field of genetics is therapy. Nonetheless, there is a considerable delay between identifying the genetic source of a problem and producing a cure. As the United Kingdom House of Commons Science and Technology Committee has noted:

While genetics is likely eventually to transform medicine, it may take some while before treatments based on genetic knowledge become available. Identifying a disease gene permits diagnosis. The ability to conduct such a diagnosis may precede discovery of the gene's functions. While a knowledge of how the gene works, when established, should, in time, lead to new drug development, through rational drug design, at present it can take fifteen years to develop and gain approval for a new pharmaceutical product.<sup>12</sup>

Presently, the only options available where the gene has been isolated are terminating the affected pregnancies or presenting people with the enormously difficult decision about whether or not they want to know

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11. John Maddox, *The Case for the Human Genome*, 352 NATURE 11, 12 (1991).

12. COMMITTEE REPORT, *supra* note 7, at xxxvi.

that they will suffer from a particular condition in the future. As one commentator put it, "there remains a serious gap between disease characterization and treatment."<sup>13</sup>

The route between attaining the knowledge and developing the therapies is one strewn with ethical, legal, and clinical hurdles. Each hurdle must be measured and judged carefully. In the meantime, our capacities grow apace. We may not have many therapies available, but we do know how to identify more genetic disorders. Maybe such identification will assist in the struggle to find cures, or at worst, in minimizing the number of those born suffering from the genetic disorder. Before considering the arguments for and against genetic screening on an individual or a society-wide basis, it is appropriate to consider whether identification or diagnosis of genetic conditions poses any questions which are different from those raised by any other form of diagnosis.

Clearly, there are many diagnoses which are distressing (e.g., a diagnosis of a condition which is not genetic in its basis). Equally, many diagnoses are not followed by therapy. To return to the example of HIV-status, diagnosis of seropositivity is generally followed by the onset of full-blown AIDS and ultimately death. Accordingly, the question must be asked: Why should society be particularly concerned about genetic diagnosis?

The answer is that, in many ways, the diagnosis of a genetic disorder, or even of a carrier status, is different from the diagnosis of other conditions because the ramifications of the diagnosis go far beyond the individual concerned. The peculiarity of genetic conditions is that they also affect the individual's family. While health-related information is generally regarded as being an inherently private matter, and the confidentiality of diagnostic information is usually jealously preserved by doctors, tensions may emerge when the traditional principles of medical ethics are tested in genetic disorder cases. This is because the four principles said to underlie health care—beneficence, nonmaleficence, autonomy, and justice or equity—are inherently individualized concepts. That is, these principles focus on the *specific* patient to the exclusion of other actual or potential patients. Yet, genetic information is not information merely about that one individual, and the doctor may feel she has obligations of the same specific type to others actually or potentially affected by the diagnosis in question.

The historical view of the relationship between doctor and patient has

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13. Theodore Friedman, *Opinion: The Human Genome Project—Some Implications of Extensive "Reverse Genetic" Medicine*, 46 AM. J. HUM. GENETICS 407, 411 (1990).

been that, in its best manifestations, it is an exclusive and intimate relationship depending on secrecy, confidentiality, and trust. Arguably, only the fourth principle of medical ethics, that of justice or equity, could readily encapsulate the problems posed by the interrelationship between genetic information about one person and its relevance to others, because it could be taken to imply a broader, more utilitarian ethic. Yet, neither justice nor equity are easy concepts to define, and to use them as a justification for genetic screening or the dissemination of genetic information even to other identifiable individuals, requires evidence of utility—evidence which is difficult to come by. This is especially true where utility is defined in terms of curability, as has already been noted. As stated by one commentator, “[i]t could be said of molecular biology that, insofar as human genetics is concerned, it has gained a scientific empire but not yet found its real clinical role.”<sup>14</sup>

Since this Article is about children, little attention will be paid to the issues raised by prenatal screening when, arguably, there is no child. However, it would be remiss to ignore this area for two reasons. First, prenatal screening in the absence of therapy will probably remain the most common kind of screening. Second, the view that “there is no child” is a hypothesis which a number of people in various communities would hotly dispute. Of course, the second consideration is not capable of resolution by this writer, but the first can be reasonably addressed.

The growth of prenatal diagnosis based on genetic screening has been exponential. Writing in 1985, Daniel Kevles pointed to the following:

Amniocentesis and legalized abortion together stimulated a major boom in prenatal genetic diagnosis. Prior to 1976 only some five thousand prenatal diagnoses of genetic disorders seem to have been carried out in the United States, and about seventy-five hundred were conducted in Great Britain. After that date, the number rose rapidly in both countries, reaching at least twenty thousand annually in the former and seven thousand in the latter.<sup>15</sup>

There is every reason to believe that this growth has continued. It is now routine in most developed countries to offer some form of prenatal genetic screening. In addition, advances in both screening capacity and the number of conditions which can be detected seem likely to presage more diagnostic intervention in pregnancy. “It seems that we are being sub-

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14. John Davis, *Genetic Testing for Familial Hypertonic Cardiomyopathy in Infants: Ethical Issues*, 310 *BRIT. MED. J.* 856, 858 (1995).

15. KEVLES, *supra* note 2, at 257.

jected to a second wave of evangelistic screening fervor generated, at least in part, by dramatic advances in diagnostic technology."<sup>16</sup>

One of the most controversial features of this drive towards prenatal screening is that there is an expectation that those who find themselves to be carrying an affected child will terminate their pregnancy. Failure to terminate in such circumstances has led some commentators to point out the danger that people who knowingly bring affected children into the world might be accused of "reproductive irresponsibility."<sup>17</sup> For this reason, the conclusion of the House of Commons Committee is to be welcomed. In their view:

[I]f the purpose of any test is to allow parents to consider whether to continue with an affected pregnancy, this should be made clear and the parents should be given the choice of whether or not to take the test. If a test shows evidence of a genetic disorder and the parents decide on abortion, that is allowed under the present law and the decision should be respected. However, if parents decline the test, or decide to carry affected children to term, they should also be supported in their decision . . . . Screening is only acceptable if it rests on free and informed consent.<sup>18</sup>

Even more controversial, however, is the possibility of presymptomatic testing for late-onset disorders (in which early treatment or surveillance for complications would not be helpful) and testing for carrier status.<sup>19</sup> Clearly, an important group for inclusion in such screening programs would be the very young. There may be many reasons why the funders of health care (whether state or private) would have an interest in encouraging such programs. They may argue that prior knowledge of the numbers of people affected by potentially resource intensive conditions would permit rational allocation of their resources.

A recent report of the U.K. Working Party of the Clinical Genetics Society ("Working Party"), which looked specifically at the area of resource allocation, is worth considering.<sup>20</sup> The Working Party's reason for concentrating on this area was that other genetic testing has had an obvi-

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16. SCOTTISH FORUM FOR PUBLIC HEALTH MEDICINE, TOWARDS A SCREENING FOR SCOTLAND 45 (D. Stone & S. Stewart eds., 1994).

17. Lori A. Whittaker, *The Implications of the Human Genome Project for Family Practice*, 35 J. FAM. PRAC. 294, 296 (1992).

18. COMMITTEE REPORT, *supra* note 7, at xl (emphasis omitted).

19. Working Party Report, Clinical Genetics Society (U.K.), *The Genetic Testing of Children*, 31 MED. GENETICS 785, 787 (1994) [hereinafter Working Party Report].

20. *See id.* at 785-97.



ous and relatively immediate clinical goal, and therefore, that testing could be seen as an ordinary clinical practice not subject to ethical or other dilemmas beyond the norm. However, the implications of screening for late-onset conditions are considerably more grave, and certainly raise profound ethical questions.

The Working Party broadly traced the arguments for and against genetic testing in these two areas and made general recommendations based on a consensus of its members. In their view, there were a number of arguments against such testing, which centered substantially on the impact of the tests on the individual child. Acknowledging the possibilities of discrimination, the Working Party also addressed themselves to the personal impact on the child as he or she develops into maturity. Where the diagnosis has no direct impact on the health of the child, they suggest that testing, and knowledge of test results, have a number of negative implications. For example, they may lead to the loss of self-esteem, affect the way in which the child is treated in the family or the wider community, prevent a later exercise of autonomy by taking the decision about testing out of the hands of the potential adult, and breach current U.K. policies on the need for counseling before or in tandem with screening.

On the other hand, any benefits to be attained are only partial benefits for the child. One of these benefits is the child's capacity to come to terms with the situation sooner rather than later. It must be conceded, however, that the reality of this as a benefit will hinge on the age and maturity of the child and on the nature of the condition detected. This would seem to militate against testing at an early age. In fact, the other benefits which might accrue are substantially beneficial for others (*e.g.*, families might learn to cope and testing might also be offered to other members of the family). Again, we see the tensions that can be generated between what might be desirable for the community and the four principles of medical ethics. If we take these four principles seriously, then the balance must surely weigh against testing where there is no possibility for direct therapeutic benefit to the individual concerned. Only one of the four principles of medical ethics, namely justice or equity, depending on how it is defined, might potentially trump the other ethical principles and render testing justified. However, neither the Working Party nor the House of Commons Committee was prepared to use this trump card, concluding that children should not have genetic diagnoses for late-onset disorders.<sup>21</sup> *"Such diagnosis is only justifiable if those requesting it have fully consid-*

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21. COMMITTEE REPORT, *supra* note 7, at xxxviii.

ered all its implications.”<sup>22</sup> Clearly, the very young child will be in no position to make such a request, and there must be some doubt as to whether or not parents are lawfully able to make such a request, when it is clear that the test is not unequivocally in the best interests of the child. Testing for late-onset disorders may help the family adjust, and it may allow them to make plans, but the most likely consequences for the child will be negative.

Bearing in mind what has been said about the need to protect children and to refrain from using them to serve someone else’s purposes, the current practice at the moment is in line with a number of recommendations including those of the World Health Organization.<sup>23</sup> Specifically, the current practice is to screen routinely only for conditions that are serious and for which there is a known treatment.<sup>24</sup> This approach would seem to be in accord with the principles of medical ethics, and also reflects the goal of both society and the law to maximize the protection of children. In any event, one might argue that consent by proxy in this case is no different from any other treatment decision that parents are authorized to make “in the best interests” of their child.

Although the law is not inevitably, or even commonly, seen as a vehicle within which ethical principles are formulated or expressed, it may be interesting nonetheless to examine by analogy the probable legal response to this apparent conflict between the interests of the child and the interests of the community. From cases involving facts as diverse as taking blood from very young children for the purposes of paternity testing to decisions about contraception and sterilization, it may be possible to extrapolate the principles by which the law would approach these complex matters.

One principle that corresponds most closely to the first of the four principles of medical ethics is that something which is done without informed consent is only justifiable when it is done in the best interests of the individual. This has arisen most commonly in cases involving nonconsensual sterilization where the courts have made it clear that the interests of others have no relevance or priority.<sup>25</sup> Thus, even if justice might be

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22. *Id.*

23. SCOTTISH FORUM FOR PUBLIC HEALTH MEDICINE, *supra* note 16, 64-65 (discussing the World Health Organization’s criteria for genetic screening).

24. COMMITTEE REPORT, *supra* note 7, at xli. Phenylketonuria (PKU) is an example of such a condition. *Id.*

25. See *Re D* (a minor) (wardship: sterilization), [1976] 1 All E.R. 326; *Re Eve*, 31 D.L.R. 4th 1 (1986).

served by allowing the sterilization, if the justice was not for the individual herself then it was clearly trumped by the need to value the rights and interests of that person and not the rights and interests of others. Equally, it has to be said that concentrating on the individual's best interests also closes off a substituted judgment argument in favor of intervention, namely that the individual might have chosen it if they could have.

This has particular relevance for genetic screening. First, if the best interests of the individual are given priority, then it will be necessary to consider what the outcome of obtaining the information would be on that individual. Whether the screening is predictive or for carrier status, if it is for untreatable conditions it has been alleged that "[g]enetic or clinical screening of asymptomatic people is contentious as no intervention has been definitively proved to alter prognosis."<sup>26</sup> If this is added to the potential for devaluation and discrimination already outlined, it would seem difficult to justify this screening as being in the individual's "best interests." It is implausible to suggest that people would, under the substituted judgment test, knowingly choose in significant numbers to acquire information that has a negative consequence. Thus, even if our legal tradition embraced the use of the substituted judgment test, it too would likely militate against obtaining such information. In any event, although we allow adults to make decisions that are not in their best interests, the tradition is to *protect* children by denying them this right until they reach maturity.

Moreover, as previously discussed, the main reasons in favor of such screening relates to the interests of others. This approach was expressly precluded by the above examples. Thus, the recommendations of the Working Party are in line with the rules extrapolated from the law; namely, in the case of predictive screening, "there should be a presumption against such testing."<sup>27</sup> In relation to testing for carrier status, although conceding that "[t]he arguments here are less clear[,] . . . the working party has . . . arrived at a consensus view that carrier tests in childhood should generally be deferred."<sup>28</sup> These recommendations stand even in the face of possible benefits to others. As one commentator said, "[W]e cannot assume that making use of present patients for the good of future patients is ethically legitimate, particularly since the pa-

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26. Mark P. Ryan et al., *Genetic Testing for Familial Hypertrophic Cardiomyopathy in Newborn Infants: Clinicians' Perspective*, 310 *BRIT. MED. J.* 856, 856 (1992).

27. Working Party Report, *supra* note 19, at 791.

28. *Id.* at 792.

tients are in no position to volunteer.”<sup>29</sup>

Although the arguments seem reasonably clear, the balance will undoubtedly shift as more therapeutic potential emerges. Even though the balance may change, this does not mean that the ethical principles to be applied are necessarily subject to variation on account of clinical possibility. Whatever the predicted clinical outcome, the fundamental ethical inquiry remains the same. As is often the case, legal issues are frequently more difficult to distinguish from ethical ones. In dealing with new possibilities, the law should proceed from fundamental principles and values that can be broadly described as ethical. Although a wealth of jurisprudence exists concerning the status of children in the law, medical progress stimulates new challenges and demands innovative interpretations.

This discussion will conclude with a consideration of three main areas of legal interest that are relevant to the question of screening children for genetic conditions or predispositions. The first is the question of consent. It has already been suggested that it is difficult to find an abstract justification for endorsing the presymptomatic screening of very young children where no cure or therapy is available. The question, then, must be at what stage a child may offer his or her own consent?

Under the Family Law Reform Act 1969 (England and Wales) and the Age of Legal Capacity Act 1991 (Scotland), the capacity of children to consent to treatment is clarified (although it is not clear why Scottish Law needed the clarification). In both jurisdictions, a young person over the age of sixteen years may offer valid consent to medical treatment, although in England and Wales (but not Scotland) that same child will not always have a refusal of consent vindicated.<sup>30</sup>

Where the relevant legislation does not apply, that is where the child is under the age of sixteen years, the decision rests on the common law. *Gillick v. West Norfolk and Wisbech Hospital Authority*<sup>31</sup> is a leading case on this topic. In *Gillick*, the House of Lords sought to clarify the extent to which a child could agree without parental consent to medical intervention. This case is perhaps peculiarly suited to the question of genetic screening because it also involved medical intervention that is arguably nontherapeutic. This is of importance because both the principles of Scottish Law and court decisions in England and Wales reinforced the view that older children *could* offer a valid consent to therapy. However,

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29. Davis, *supra* note 14, at 858.

30. *Re R (a minor)* (wardship: medical treatment) 7 BMLR 147 (1992).

31. [1982] 1 All E.R. 402.

neither contraception, as in *Gillick*, nor genetic screening necessarily fit easily into the category of therapy as we might routinely describe it.

Broadly, the *Gillick* decision indicated that if the children were of sufficient maturity to understand the nature and the consequences of what they were seeking, then the doctor (who makes that decision, although on what grounds it is not clear) may lawfully proceed without reference to the parents, although they are encouraged to persuade the young person to seek the views of their parents. From the perspective of genetic screening, for doctors to proceed on a young person's request would seem to require a finding of a high level of maturity, given that the nature and consequences of screening are much more complex than decisions involving a young person's desire to avoid an unwanted pregnancy. In line with policy guidelines, the child should receive prescreening counseling,<sup>32</sup> which provides an additional opportunity to assess levels of understanding and maturity.

Although discussed previously in this Article, it is worth addressing a further question. If the child is either too young for *Gillick* competence or is found otherwise not sufficiently mature, and therefore, not authorized to agree on her own behalf, is there someone else who could agree on the child's behalf? The House of Commons Committee seems to assume that this might be possible. In rejecting mass screening for public health reasons "*unless a treatment for the disorder exists*,"<sup>33</sup> they nonetheless concluded that "[p]arents should, of course, be able to ask for genetic *diagnosis* to be carried out on a particular child where family history suggests this may be appropriate. This will become increasingly commonplace and will bring benefits by avoiding multiple referrals due to misdiagnosis."<sup>34</sup>

Diagnosis is in a sense no different from individual screening unless therapy is available. This statement reflects an ideological shift, or perhaps even some confusion over the interests at stake; for one must assume that it relates only to conditions for which some therapy is available. However, this must remain a moot point. If diagnosis of this sort is what is being referred to, then it is unclear why it is necessary to single it out because presumably it is covered in the general, applicable rules of law.

In any event, the general rule of law would seem to be that parents and

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32. COMMITTEE REPORT, *supra* note 7, at xxxiii.

33. *Id.* at xlii.

34. *Id.*

those *in loco parentis*, rather than having absolute rights over the children under their care, might be said to have responsibilities. This is a critical difference because it constrains what those with parental authority can actually do; limiting it to what is in the "best interests" of the child. But if screening for late-onset conditions is not clearly in the child's "best interests," then it is unclear on what basis it could be authorized by others, regardless of their relationship to the child.

Interestingly, the Working Party found a difference of opinion between those who might be engaged in the screening of children. They noted that "[g]eneticists and coworkers were less likely to view parental wishes alone as sufficient to justify testing than were pediatricians and others."<sup>35</sup> Indeed, the former group may be right to feel this way. The overwhelming weight of advantage in such testing is for others, not the child. As a matter of interest, one alternative to the "best interests" test or substituted judgment test might be that parental consent by proxy could be validly given to procedures which are not *against* the best interests of the child. This is a subtle, but potentially important difference, in the field of genetic testing. This standard may be difficult to satisfy, however, given the reality that diagnosis may have a profoundly negative impact on the child.

A second legal problem relates to confidentiality—the basis of the doctor-patient relationship. The fundamental principle of confidentiality is that patients have a right to expect that information that is personal to them and that is provided in the course of a confidential relationship will not be disclosed to others.<sup>36</sup> Of course, even the General Medical Council ("GMC"), the body that is responsible for setting and maintaining standards of practice in the U.K., concedes such wide exceptions to this rule<sup>37</sup> that many believe it to have been significantly eroded. Nonetheless, it remains a fundamental tenet of medical practice that confidentiality should be maintained.

Every time a diagnosis is given to a parent, the diagnosis involves disclosure of sensitive information about one person (the child) to another. This is expressly accounted for in the GMC's exceptions.<sup>38</sup> But the disclosure of genetic information regarding a child may have highly significant consequences for a child in his or her family and in other

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35. Working Party Report, *supra* note 19, at 787.

36. THE GENERAL MEDICAL COUNCIL, PROFESSIONAL CONDUCT AND DISCIPLINE: FITNESS TO PRACTISE 26 (1992).

37. *Id.* at 27.

38. *Id.*

environments. These consequences could be much greater, and potentially more negative, than the disclosure of other diagnoses. The interests of the child may not be served by giving the information to the parents, yet the parents will likely be the people who have authorized the test.

As the Danish Council of Ethics pointed out:

Because of the nature of genes, it may be argued that genetic information about any individual should not be regarded as personal to that individual, but as the common property of other people who may share those genes, and who need the information in order to find out their own genetic constitution. If so, an individual's *prima facie* right to confidentiality and privacy might be regarded as overridden by the rights of others to have access to information about themselves . . . .<sup>39</sup>

Although the question of genetic disposition clearly does involve others, if we return to the original hypothesis that society seeks to protect children *qua* children, then it might be inconsistent to apply what is essentially a utilitarian test to circumvent the provision of a right that would otherwise have been held to be of vital importance. Equally, because parents may have access under legislation to their children's medical records,<sup>40</sup> the mere acquisition of genetic knowledge about a child may threaten the confidential nature of the doctor-patient relationship to its ultimate detriment. This provides yet another reason for not screening in the first place.

A final legal issue is that of professional liability. In the U.K., the test for liability remains effectively a professional one. Although other jurisdictions (such as some states in the United States<sup>41</sup> and Australia<sup>42</sup>) have moved away from this, the U.K. appears to follow it. The test derives from the case of *Bolam v. Friern Hospital Management Committee*<sup>43</sup> (the "*Bolam* test") and effectively states that a doctor will not be negligent if she acts in accordance with a practice held to be reasonable by a responsible body of medical opinion.<sup>44</sup> Therefore, it could be said, although

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39. WORKING GROUP, ROYAL COLLEGE OF PHYSICIANS OF LONDON, *ETHICAL ISSUES IN CLINICAL GENETICS* para 4.10 (1991) [hereinafter *ETHICAL ISSUES*].

40. Access to Health Records Act, 1990 Ch. 23 § 3 (Eng.).

41. See, e.g., *Canterbury v. Spence*, 464 F.2d 772, 783 (D.C. Cir.), *cert. denied*, 409 U.S. 1064 (1972) (adopting a "prudent person" test rather than the more traditional professional model).

42. See, e.g., *Rogers v. Whitaker*, 67 A.L.J.R. 47 (Austl. 1992) (holding that the *Bolam* test was not applicable to questions of consent, particularly when direct questions had been asked by the patient).

43. [1957] 2 All E.R. 118 (Q.B.).

44. *Id.* at 121.

somewhat simplistically, that as long as some doctors are behaving in a certain way, then no liability will attach.

An interesting feature of this test relates to the dependence of legal judgment on accepted medical practice. The evidence obtained by the Working Party suggested that, for the moment at least, practices vary.<sup>45</sup> This makes it likely that a responsible body of medical opinion will be found to endorse whatever the individual doctor has or has not done, thereby virtually ensuring that legal liability will not be attributed. However, it should be said that there is an increasing trend in contemporary medicine to develop codes of practice that might be thought of as codes of best practice. If such codes are developed in relation to genetic screening, it will become harder to argue in favor of the doctor who deviates from that code, at least under the *Bolam* test. If this occurs, then the U.K. courts will probably return to the test outlined in *Hunter v. Hanley*,<sup>46</sup> which effectively asks whether or not any doctor acting with due skill and care would have also followed the challenged practice. Under either test, the attribution of liability will be difficult to secure.

It has been said by some that the new genetics does not create any new ethical problems. Even if this is true, it certainly poses the old dilemmas in stark new ways. The Royal College of Physicians of London noted:

The fact that the problems are essentially the same suggests that to the extent that certain ethical standards are applicable in other areas of medicine, these will apply equally in the context of genetics. However, some new considerations do arise in genetics, and they at least raise the question of whether the familiar problems should always be approached by means of familiar ethical standards.<sup>47</sup>

This is the heart of the problem. It is often said that law and ethics lag behind medicine and science. For example, Australian Judge Windeyer colorfully described the law's relationship with medicine as being "in the rear and limping."<sup>48</sup> Equally, even if there are no new ethical problems posed, this does not mean that we have resolved the question of which ethical considerations can or should be applied to the new problems raised. Rather, it may mean that, in the abstract, we have the means to decide. In addition, what has gone before may also suggest that medicine and science are running ahead of themselves. Because

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45. See Working Party Report, *supra* note 19, at 786.

46. 1955 Sess. Cas. 200, 206 (Scot. 1st Div.).

47. ETHICAL ISSUES, *supra* note 39, at para. 4.3.

48. Mount Isa Mines, Ltd. v. Pusey, 125 C.L.R. 383, 395 (1970).



medicine and science do not develop in a vacuum, those who practice these professions must also have a framework within which to operate safely and appropriately, both for the sake of their patients and themselves. Therefore, if we are to offer adequate protection to children as defined earlier, it seems that scrutiny of our decisions must take account of a further test to the four principles of medical ethics outlined above. As has also been suggested, what the test should be is by no means clear. We purport to protect children, but seem to have no clarity of content to the test which should apply in pursuit of this goal.

This brief review suggests that ethical analysis is by no means as sophisticated as it would need to be if we are to combine the best of medical ethics with a rational respect for children. The Working Party report shows acute sensitivity to this, yet may be seen by some as a stultifying progress. In recognition of this, the House of Commons Committee proposes the creation of a Human Genetics Commission which, among other responsibilities, has the power to "*prescribe the circumstances in which particular types of screening or diagnosis, such as pre-natal diagnosis, should be provided or proscribed.*"<sup>49</sup> This is a radical proposal because it favors legislative intervention in the practice of medicine. Yet, given the complexities and the implications of the new genetics, it is one which this author very much welcomes.

The creation of such a Commission will not supply the answers to the fundamental ethical dilemmas outlined here. The acquisition of genetic knowledge potentially sets the individual and the community against each other for two reasons. First, the individual whose genetic makeup is known might be thought to have a moral obligation of disclosure to those who may also be affected. Yet, this obligation is not generally held to exist in other circumstances. Medical information is seen as among the most private of all, and overriding that "privacy" right requires forceful justification. In the case of genetic information, the principle used to justify overriding the privacy right would be the benefit to others which would be achieved. This is a classic utilitarian approach, and therefore often unpopular. In any event, to impose a moral obligation to disclose genetic information would be to impose a duty to rescue—one which the law does not require, save in exceptional circumstances.<sup>50</sup> Indeed, it may be that this is a new ethical problem posed by genetic science.

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49. COMMITTEE REPORT, *supra* note 7, at lvi.

50. For example, where there is a preexisting duty of care, as in the doctor-patient relationship.

Second, genetic information has wider public dimensions. It might be argued that insurers, employers, sexual partners, and those who are responsible for the allocation of health care resources also have a right to this information. The public interest might therefore equally be invoked as a justification for dissemination of otherwise private information. We would be well-advised, however, to recognize the caution of Judge Rose in the case of *X v. Y*,<sup>51</sup> that there is a difference between what is in the public interest and what interests the public.

Thus, as the Danish Council of Ethics succinctly stated:

[I]t can be said that a decisive stand on the new challenges must be based on a choice between the two overall approaches: the utilitarian view or the approach based on the help motive and respect for the individual. The question, in other words, is: must the principal purpose of applying human genetics be formulated in terms of the gain for the common good or in terms of the individual?<sup>52</sup>

Manifestly, this is not a question soluble within or by any one discipline. It merits and demands public debate. As stated by the House of Commons Committee, "[t]he dilemmas that genetics poses will be resolved by the public and parliamentary debate, not by academics alone. But that debate must be well informed, both about the science itself and about its ethical, legal and social implications."<sup>53</sup> Arguably, such debate is particularly important when the vulnerable, such as children, are a likely target group.

However, public debate requires public understanding of the issues, which in turn demands that the public is given access to the information needed to formulate relevant questions and reach appropriate conclusions. The responsibility, therefore, rests on the educational process, the media, and the scientists themselves to ensure that such a debate can occur. In the case of children, public understanding must be additionally informed by a thorough analysis of the responsibility that the community has to children by an honest assessment of the tests that we apply when making decisions on their behalf.

In conclusion, and with peculiar resonance with respect to vulnerable groups such as children, "[a] broad public understanding of the scientific basis of medical genetics is essential if informed public policy decisions are to be taken about the introduction of genetic screening programmes.

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51. [1988] 2 All E.R. 648, 658 (Q.B.).

52. DANISH COUNCIL OF ETHICS, *supra* note 10, at 64.

53. COMMITTEE REPORT, *supra* note 7, at lxxxv.

Such programmes . . . have both an individual and a public dimension.”<sup>54</sup> The task, therefore, is informative and educational rather than scientific or clinical. We may, in recognition of this reality, carry a responsibility to present and future generations to moderate the pace of scientific inquiry to accommodate the ethical debate—not merely to do something because we can.

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54. NUFFIELD COUNCIL ON BIOETHICS, *GENETIC SCREENING: ETHICAL ISSUES* 75 (1993).